

Disability Leadership Fellowship

Submitted by Andrew Morris, Oregon Institute on Disabilities and Development
June 9, 2003 through July 30, 2004

Final Report

The Disability Leadership Policy Fellowship this past year has been an amazing experience that is difficult to put into the words that can express the gratitude I have for AUCD, the network, the board, and my home UCEDD. Whether participating in meetings with AUCD members, Congressmen, Hill staff, Administration officials and staff, the experience has burned into my mind the need to "fight the good fight" to help improve the lives of people with disabilities.

My principal activities can be broken down into coalition work, policy related work, and LEND activities. A large part of my time was spent on technical assistance to the UCEDD network to which most of my activities contributed.

Coalition Work

Within my first week at AUCD, I became involved with the Consortium for Citizens with Disabilities (CCD) of which AUCD is a member. I represented AUCD on the Health and Long Term Services Task Forces. I am proud to relate that one of the task force co-chairs said they should have made me an honorary co-chair because of all the contributions I made to the task force. I also attended the monthly meetings of the CCD co-chairs with Donna Meltzer and Kim Musheno where the leaders of the consortium share news and coordinate legislative strategies on a wide variety of disability policy issues. This provided a good opportunity to find out what was happening on other disability issues and learn from very experienced leaders in the field.

Another coalition with which I was active was a Medicaid coalition that is made up of a variety of national interest groups. I was able to develop relationships with individuals and health care leaders within the coalition that provided opportunities for AUCD to provide input and impact the work of the larger health care community.

Other coalitions in which I participated included the Leadership Conference on Civil Rights, a coalition developed to win passage of the Family Opportunity Act, and a coalition around Medicaid waiver activity. The coalition around the Family Opportunity Act is made up of disability and family advocates who have worked closely with Congressional staff. The Leadership Conference has recently started a new effort around grassroots organization and is really hoping to have the disability community involved. The ad hoc waiver coalition, formed by the

Center on Budget and Policy Priorities, was a useful tool to keep the AUCD network and specific UCEDD directors updated on items that could potentially affect them.

Having spent a lot of time working with coalitions this past year has really made a strong impression on me. Coalitions provide good opportunities to help fulfill the mission of your association. It also helps individuals to learn how to work collaboratively with others who may or may not have the same position on an issue. It has also been a good experience to see how coalitions are built around specific topics.

Legislative and Public Policy Work

The majority of my time at AUCD has been spent working on policy and legislative issues. Policy areas that I concentrated on were: the President's New Freedom Initiative (NFI) related to Medicaid; the Family Opportunity Act; Medicaid waivers and other reform proposals; Medicaid reimbursement in the territories; and the new Medicare Modernization Act. Most of my work with the New Freedom Initiative (NFI) has focused on the draft legislative proposal developed by the Administration containing the Money Follows the Person and other demonstration proposals. Over this past year, I have worked closely with CCD counterparts on developing analyses, positions, and recommendations for the draft legislation. As well as working with Hill staff on the NFI, I also attended several conferences that were sponsored by the Administration on the concept of helping people with disabilities to live and participate in their communities. Working on the initiative also helped to strengthen relations of the network with the Centers for Medicare and Medicaid Services.

Another piece of legislation that I worked closely on was the Family Opportunity Act (FOA). As mentioned above, I was involved in a coalition that worked to pass the FOA. At this time, the bill has passed the Senate, but has been held up in the House. I was able to participate in negotiations between interested parties and Hill staff on strategies for moving this important legislation. This Spring I spent a lot of time working on the Medicaid and CHIP Safety Net Preservation Act of 2004 that was introduced by Senator Max Baucus (D-MT). I was invited to work with a small group on the legislation because of relationships I had developed with staff from both parties. The proposed legislation would prevent the Administration from granting Medicaid waivers that would cap spending or block grant the Medicaid program. Most of my work with this legislation was to try to help bipartisan co-sponsorship of the bill through contacts with congressional staff and using UCEDD directors in targeted states to communicate with their Senators. One way I accomplished this was to contact UCEDD Directors in key states, who in turn, were able to communicate with their Senators and educate them on the issue.

At the request of the UCEDD directors in the US Territories, we worked with Congressional members and staff around the Medicaid reimbursement issue in the territories. This was a new issue that was added to AUCD's legislative agenda this year and I was asked to provide staff leadership on the issue. The territories are capped at a 50 percent matching rate. I had conversations with and met with key staff in both the House and Senate to educate them about the issue. While the issue was of concern to most of the staff with whom I talked, the leadership did not support increasing the cap because it would have been an extension of the Medicaid program and some thought too costly.

Following the passage of the Medicare Modernization Act of 2003, I researched and prepared a summary of the major provisions that affect people with disabilities. This summary was sent to the network and posted on the web site.

LEND Work

The LEND experience I had before coming to the Central Office allowed me to become involved in LEND activities at AUCD. The primary LEND activities that I was involved in were the Virtual Trainee, the Health Administration discipline meeting, and the Health Administration curriculum work group. Last fall I was able to choose the current Virtual Trainee, with guidance from AUCD staff. Until the new LEND staff was hired at AUCD, I was the main contact person for the Virtual Trainee. I worked with him to coordinate trainee activities at the annual meeting. With my background as a Health Administration trainee and MCHBs' interest in the future of the health administration discipline MCHB staff and AUCD decided that the 2004 discipline meeting would focus on health administration. Over 30 people gathered in Washington, DC to discuss the discipline, where it has been and where it is going. At the conclusion of the meeting, a work group was formed to review the existing curriculum and rework it into competencies that health administration trainees should possess after completing their LEND experience. The competencies will be presented to the LEND directors at the next Annual Meeting.

Looking back over the last 14 months, there are several contributions I believe I made to the Central Office and AUCD network. Some of the contributions include building new and stronger relationships with staff within the Centers for Medicare and Medicaid Services (CMS) and Hill staff; forming a new Medicaid workgroup within the AUCD network; and contributing to the *Legislative News In Brief*. Twice this year I attended meetings at CMS in Baltimore with George Jesien, Jan Nisbet, and Mark Swanson. Through the meetings and conferences that I attended, I was able to develop a trusting relationship with various CMS employees. As trust was developed, AUCD and CMS employees were able to share information back and forth that helped to benefit both organizations. As

well as developing relationships with Administration officials, this year provided the opportunity to develop relationships with Hill staff that will continue to benefit AUCD and my home UCEDD after returning to Oregon. I was able to connect successfully with key committee and member staff. I was also able to develop relationships with staff in Congressional offices of the Oregon delegation. These are relationships I hope to continue to foster and grow after returning to Oregon.

Another major activity for me was the establishment of the AUCD Medicaid Workgroup. I worked with AUCD Board members and the AUCD executive Director to get the workgroup started. At first the workgroup was intended to be a small group to help AUCD formulate a position and develop principles for Medicaid reform. The association's workgroup ended up having close to 60 members. The workgroup became more of a dissemination tool and a quick way for the Central Office to receive feedback on legislative proposals related to Medicaid from the network. I have received very positive feedback from the members of the workgroup as they have found the disseminated information very useful. I believe that the workgroup will continue and will be able to provide a place where thoughtful feedback can and will be shared and sent to the Board of Directors and the association as policy work continues in this important arena.

I have also worked closely with Kim Musheno each week on the *Legislative News In Brief*, the newsletter that goes to the association to update them on disability-related legislation as well as other Capitol Hill news. During Kim's maternity leave, *Legislative News In Brief* it became my responsibility to gather the information and provide the first draft of this popular newsletter. Working on the newsletter taught me how to convey information in the most informative but concise way.

While working at the Central Office, I have also tried to contribute to the needs and interests of my home UCEDD, the Oregon Institute on Disabilities and Development (OIDD). As I have developed relationships with staff from the Oregon Congressional delegation, OIDD has also been able to use the contacts to educate and inform these members about the needs of people with disabilities and the impact of current and proposed policies. I feel that because of our communications OIDD staff have gained a deeper understanding of Medicaid activities at the federal level and knowledge of some of the key players. As these relationships become stronger, it could be a large benefit to OIDD. As OIDD becomes more involved with state Medicaid activities, it could become a resource that state officials will rely on.

This past year, combined with my LEND experience, has had a tremendous impact on my career. Disability policy has become a large part of my life. The

ability to advocate for changes that will positively impact a person's life is something that I want to continue. There are many different areas in which a person can work in the disability field, from direct services to research to advocacy. Advocacy is an area in which I feel that I have developed some talent. The areas that I want to continue to work in are disability and health policy at the federal level. When I first entered the LEND program, I had planned on doing LEND for a year and then moving on to something else. Obviously, I didn't move on to another area and stayed within the disability field. This past year has allowed me to become educated on how things work at the federal level. Having that experience, combined with previous state experience will be a benefit when I return to OIDD. I have really enjoyed working at the federal level. While state level advocacy can be more intimate, and you can see the fruits of changes to state law, the federal level allows for an opportunity to impact the whole country. It is my desire to return to the federal level at some point in my career.

Again, I would like to thank AUCD for the opportunity to participate in the fellowship and gain knowledge of the network and how things work at the national level.